DOCUMENT RESUME

ED 067 783 EC 050 051

TITLE	Residential Programming for Mentally Retarded Persons. Volume I, Prevailing Attitudes and Practices in the Field of Mental Retardation.
INSTITUTION	National Association for Retarded Children, Arlington, Tex. South Central Regional Office.
SPONS AGENCY	Social and Rehabilitation Service (DHEW), Washington, D. C. Div. of Developmental Disabilities.
PUB DATE	72
GRANT	OEG-56-P-70771-6-01-(R-1)
NOTE	21p.
EDRS PRICE	MF-$0.65 HC-$3.29
DESCRIPTORS	*Community Attitudes; *Exceptional Child Services; Institutionalized (Persons); *Mentally Handicapped; *Parent Education; *Residential Programs

ABSTRACT

The first of a series of four booklets on residential programing for the mentally retarded reviews for parents the prevailing definitions, attitudes and practices in the field. Mental retardation is defined as subaverage functioning which originates during the developmental period and is associated with impairment in adaptive behavior. The need for community based residential programs (group homes, hostels, apartments) is said to be underscored by the fact that traditional institutional programs serve only four% of America's over six million mentally retarded. The following aspects of services for the mentally retarded are discussed: emphasis on institutionalization, assumed roles of institutions, meeting the needs of residents in institutions, and the role of parents. It is asserted that, traditionally, the rights of the retarded in the community (regarding education, marriage, personal autonomy, housing requirements, legal rights) and in institutions (regarding integration of men and women, educational and training programs, exploitation, discipline) have been abused, abridged, or denied. (For related information, see EC 050 052 through EC 050 054.) (GW)

ED 067783

RESIDENTIAL PROGRAMMING FOR MENTALLY RETARDED PERSONS

1

Prevailing Attitudes and Practices in the Field of Mental Retardation

EC 050 230 E

ED 067783

RESIDENTIAL PROGRAMMING FOR MENTALLY RETARDED PERSONS

Prevailing Attitudes and Practices in the Field of Mental Retardation

This series of materials was developed in conjunction with the NARC project **Parent Training in Residential Programming,** supported by grant 56-P-70771-6-01 (R-1) from the Division of Developmental Disabilities, Social and Rehabilitation Service, U. S. Department of Health, Education, and Welfare.

National Association for Retarded Children
2709 Avenue E East, Arlington, Texas 76011

1972

2

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
OFFICE OF EDUCATION
THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL OFFICE OF EDUCATION POSITION OR POLICY

ACKNOWLEDGEMENTS

For their generous help and cooperation during the development of these materials, we would like to express our appreciation to:

Frank J. Menolascino, M.D.
Board Coordinator for Program Services
National Association for Retarded Children

Philip Roos, Ph.D.
Executive Director
National Association for Retarded Children

H. David Sokoloff, AIA
Chairman, Residential Services & Facilities Committee
National Association for Retarded Children

We are particularly grateful to the Division of Developmental Disabilities, Social and Rehabilitation Service, U. S. Department of Health, Education, and Welfare, for their financial support of this project.

Max R. Addison, M.S.
Project Coordinator
Parent Training in Residential Programming
National Association for Retarded Children

Robert E. Luckey, M.S.
Consultant, Program Services Department
National Association for Retarded Children

Brian M. McCann, Ph.D.
Assistant Executive Director for Program Services
National Association for Retarded Children

PREFACE

Standards for residential facilities have been developed, and we are in the process of designing similar standards for community programs. Now the question remains: how can these standards best be implemented to insure quality programming? In this regard, parents have been generally hesitant to ask questions concerning the nature of programs for the mentally retarded. The materials that follow review for parents and other representatives of consumers of residential services the prevailing definitions, attitudes and practices in the area of residential programming. They also discuss needed modifications in traditional residential models, areas of program emphasis, evaluation procedures, and strategies for implementing change in existing facilities.

Today, more than 200,000 mentally retarded persons live in approximately 175 public residential institutions, while up to 60,000 persons reside in private facilities (NARC, 1971). Commenting on present day conditions, the President's Committee on Mental Retardation (PCMR, 1968) reports that institutions for retarded persons are usually located in remote areas and are characterized by inappropriately designed, overcrowded and antiquated buildings. The problem is compounded by the fact that most residential personnel are underpaid, poorly trained and often have little chance of achieving better working conditions or advancement. It is widely recognized that former concepts of "custodial care" are no longer acceptable. Parents as well as professionals are becoming increasingly vocal in their demands that every retarded resident be provided with an institutional program designed to optimize his development level — regardless of ultimate functional potential. NARC has means for auditing these mental retardation programs throughout the nation, being represented in 50 states by some 1500 State and Local Associations. However, NARC firmly believes that in order to have a significant impact upon residential programming, the Association must better inform its constituents concerning existing problems and constructive approaches which will lead to improvements.

Early steps to clarify the evaluation of residential services were taken in 1952 by the American Association on Mental Deficiency. A significant outgrowth of AAMD's early evaluative efforts was the formation in 1966 of the National Planning Committee on Accreditation of Residential Centers for the Retarded. Member organizations of the National Planning Committee were the AAMD, American Psychiatric Association, the Council for Exceptional Children, the United Cerebral Palsy Association and NARC. In 1969, the Accreditation Council for Facilities for the Mentally Retarded evolved from the National Planning Committee. Standards for residential facilities (ACFMR, 1971) were adopted in May, 1971, and

the voluntary accreditation of residential facilities began in early 1972.

In an effort to effectively involve parents in residential programming and the new accreditation process, NARC (through funding by H.E.W.'s Division of Developmental Disabilities) has developed the present training materials. The materials are intended to help parents and other concerned citizens to become more knowledgeable consumer-representatives, so they can become significantly involved in program planning and evaluation.

The training materials are organized into four sections:

I. Prevailing Attitudes and Practices in the Field of Mental Retardation;
II. A Developmental Model for Residential Services;
III. Developmental Programming in the Residential Facility;
IV. The Process of Change.

This series is designed to acquaint the reader with current information, attitudes and practices related to residential services, and provide basic information regarding specific residential training programs and suggested strategies for achieving improved residential services. The materials are intended for use in conjunction with a seven-hour workshop consisting of structured audio-visual presentations and group exercises. These training materials are available through the six NARC Regional Offices. The addresses of the Regional Offices are as follows:

Northwest Regional Representative
4706 Lacey Boulevard
Lacey, Washington 98501

Southwest Regional Representative
1842 El Camino Real, Suite 1
Burlingame, California 94010

North Central Regional Representative
737 Michigan National Tower
Lansing, Michigan 48933

Southeast Regional Representative
3950 Peachtree Road, N.E.
Suite 115
Atlanta, Georgia 30319

Northeast Regional Representative
420 Lexington Avenue
New York, New York 10017

South Central Regional Office
2709 Avenue "E" East
Arlington, Texas 76011

Prevailing Attitudes and Practices in the Field of Mental Retardation

Our future is deeply trainted by our past, and today's reactions to the mentally retarded still carry the imprint of negative and destructive definitions and labels. This section attempts to review many of these current attitudes and practices, particularly as they relate to the provision of services in residential facilities for retarded persons.

THE PROBLEM OF DEFINITIONS

Over the years, there have been many definitions of mental retardation which attempted to differentiate between the intellectually subaverage and those persons having "normal" intelligence. Unfortunately, these definitions have generally been couched in extremely negative terms. Early definitions of the problem have included the following:

> **Mental deficiency is a state of social incompetence obtaining at maturity or likely to obtain at maturity, resulting from developed mental arrest of constitutional origin; the condition is essentially incurable through treatment and unremediable through training except as a treatment in training instills habits which superficially or temporarily compensate for the limitations of the person so affected while under favorable circumstances and for more or less limited periods of time (Doll, 1941).**
>
> **Mental defectiveness represents a condition of mental nondevelopment, arrest, deficiency, or deterioration which is very grave and permanent, which dates from early life, and which always effects the intelligence, judgment, or understanding and the capacity for social and economic adjustment (Wallin, 1949).**
>
> **A mentally defective person is a person who is incapable of managing himself and his affairs, or being taught to do so, and who requires supervision, control, and care for his own welfare and the welfare of the community (Benda, 1954).**
>
> **Mental retardation refers to a condition of intellectual inadequacy which renders an individual incapable of performing at the level required for acceptable adjustment within his cultural environment (Masland, 1963).**

In addition to these general definitions, a number of terms have been used to define varying degrees of mental retardation. Such unfortunate misnomers as "idiot", "imbecile", "moron", "low-grade", "high-grade", "custodial", "trainable", and "educable" were once, and in some cases still are, used to describe the retarded. These terms not only set the mentally retarded apart from other members of society, but convey a picture of subhuman status,

prolonged dependence, and a seriously restricted ability to develop or learn. Such images have all been employed as justifications for isolation from the community, custodial care and over-protection.

One of the most harmful effects of past definitions and related terminology is their negative impact upon the attitudes and expectations of persons directly or indirectly responsible for the care, education and training of the mentally retarded. Thus, self-fulfilling prophecies are set in motion which work against successfully maximizing the retarded person's level of functioning. For example, once labeled as custodial, a retarded person's living and learning environments are likely to be structured to reflect that label. A person incapable of benefiting from more than custodial care is incapable of learning and development, isn't he? Then, education and training programs are unnecessary for persons who cannot learn . . .

On the basis of this type of reasoning, retarded persons are frequently denied appropriate educative programs, thereby preventing further learning and development. Thus, the original prophecies are "confirmed".

This is not to say that labeling, in itself, is necessarily destructive. Categorization and classification are basic to scientific inquiry. However, in the case of human beings, it is too often assumed that once a person has been tagged "diabetic", or "mildly retarded", such a label will automatically provide appropriate services. In theory, at least, labeling **should** serve as a first step toward needed services. Unfortunately, in the case of the mentally retarded, labels are too often used as an excuse for exclusion from benefits and services ordinarily available to nonretarded persons.

A Widely Used Definition

A definition of mental retardation which is generally accepted in the United States was adopted by the American Association on Mental Deficiency in 1961. This definition (Heber, 1961) states that:

> **"Mental retardation refers to subaverage intellectual functioning which originates during the development period and is associated with impairment in adaptive behavior."**
>
> **The terms used in this definition may be explained as follows:**
>
> **SUBAVERAGE GENERAL INTELLECTUAL FUNCTIONING: Falling below 97% of the population on standardized tests of global intelligence (i.e., tests which attempt to measure vocabulary, comprehension, memory, reasoning, judgment and visual-motor functions).**
>
> **DEVELOPMENTAL PERIOD: From conception to about 16 years of age.**
>
> **ADAPTIVE BEHAVIOR: The ability to adapt to and control one's environment, usually defined in terms of maturation, learning and social skills.**

It should be noted that the AAMD definition is based upon a dual concept of mental retardation. That is, mental retardation is defined in terms of reduced intellectual functioning which, in turn, is associated with deficits in maturation, learning and the development of social skills. Even though this definition is more general than earlier statements and does not emphasize the deficiencies and disabilities of the mentally retarded, it still does not adequately stress the learning, growth and developmental potentials that exist for mentally retarded persons.

DIAGNOSIS MAY BE DIFFICULT

No person should be classified as mentally retarded until he has been evaluated by a team of qualified professionals — including representatives from the social, educational, psychological and medical disciplines. Moreover, the assessment should not be considered complete unless parents or relatives have been involved in the evaluation process as significant observers, and the person's adaptive behavior has been assessed **in relation to his community and family situation, taking into account the cultural norms of his environment.**

As indicated above, the diagnosis of mental retardation is made on the basis of two dimensions: (1) measured intelligence; (2) adaptive behavior.

Measured Intelligence

A primary tool used in the diagnostic process is the standardized intelligence test. Tests of this type are used to sample a wide range of knowledge and skills in order to compare a person's test performance to a standard established for his age level. A person exhibiting knowledge and skills similar to the standard for his age group is considered average. Below and above average performance, therefore, means that a person's test performance is comparable to persons either younger or older than himself.

Several tests are commonly used to measure general intellectual functioning in children and adults. The most frequently used are the **Stanford-Binet Intelligence Scale,** the **Wechsler Intelligence Scale for Children,** and the **Wechsler Adult Intelligence Scale.** The Stanford-Binet measures a wide range of abilities corresponding to various mental ages, while the Wechsler Scales for Children and Adults are separated into specific skill areas with performance compared to the average abilities of persons at different chronological ages.

Persons attaining IQ's significantly below 100, (100 is considered to be average), are usually classified according to levels of mental retardation as follows:

Level of Retardation	Standardized Intelligence Test	
	Stanford-Binet	Wechsler
Mild	52 - 67	55 - 69
Moderate	36 - 51	40 - 54
Severe	20 - 35	25 - 39
Profound	Below 20	Below 25

The classification of "borderline mental retardation" is also frequently employed (IQ's of 68-83 and 70-84 on the Stanford-Binet and Wechsler Scales, respectively). It is felt, however, that persons falling within this group should not be considered as mentally retarded. Rather, they are individuals whose measured intelligence falls between the mentally retarded and the "normal" ranges.

Basic to the use of intelligence tests is the assumption that **the person taking the test has had similar opportunities to learn and shares a common language and culture with those persons on whom the test was standardized.** Such an assumption appears obvious. Still, the 1970 litigation, Dianna *vs.* California Board of Education, was won by the plaintiff on the grounds that some 22,000 Mexican-Americans had been entrapped in classes for the mentally retarded because they were given allegedly culturally unfair tests in English rather than Spanish. Clearly, a number of factors other than intelligence can significantly depress test scores. These include sensory impairments, motivation to perform well in a testing situation, anxiety associated with test taking, and so called "mental illness". Therefore, the classification of mental retardation should be applied only to those persons who, after a comprehensive and appropriate evaluation, **continue** to function at a significantly subaverage level — even after various attempts at remediation have been made.

Adaptive Behavior

The second criterion used in diagnosis of mental retardation is adaptive behavior. In the AAMD manual on terminology and classification, Heber (1959) defines adaptive behavior as follows:

> **"The dimension of adaptive behavior refers primarily to the effectiveness with which the individual copes with the natural and social demands of his environment. It has two major facets: (1) the degree to which the individual is able to function and maintain himself independently, and (2) the degree to which he meets satisfactorily the culturally-imposed demands of personal and social responsibility" (p 61).**

As in the case of measured intelligence, adaptive behavior is evaluated by comparing an individual with members of his own age group. Thus, Heber points out that, ". . . **adaptive behavior** is always evaluated in terms of the degree to which the individual

meets the standards of personal independence and social responsibility expected of **his** chronological age group" (p 61).

Thus, **maturation** would be emphasized during early childhood years in which such skills as sitting, standing, walking, self-feeding, toileting and speech are ordinarily developed. Academic performance would be stressed during school age years, while vocational and social effectiveness would be appropriate topics for adults.

Adaptive behavior is more difficult to assess than intellectual functioning due to a lack of satisfactory measures. The **Vineland Social Maturity Scale** is a common tool for evaluating adaptive behavior. This instrument must, however, be supplemented by other sources of information regarding the individual's everyday behavior if an adequate assessment is to be made.

A positive correlation should exist between measured intelligence and adaptive behavior. That is, an individual who ranks relatively high in one dimension would be expected to rank high in the other area as well. Marked discrepancies between measured intelligence and adaptive behavior (e.g., an intelligence quotient within normal limits coupled with a subaverage adaptive behavioral level, and vice versa) would cast serious doubt upon the diagnosis of mental retardation.

The Eternal Child

In the diagnostic or evaluative process, there is a danger of approaching the mentally retarded person as an "eternal child". Diagnostic conclusions such as, "This child will always have the mind of a five year old", are overly common. Obviously, this approach places unnecessary limitations on the development of the retarded person — no one "expects" them to progress beyond the dependent stage of childhood. The retarded individual, then, may be treated as a child even during his adult years, preventing development of the independence associated with adult maturity.

It must be remembered that a retarded person's "mental age" does not necessarily reflect his social interests and needs. Thus, while the performance of a mildly retarded adolescent on a standardized intelligence test may approximate that of a non-retarded ten year old, it is likely that his social interests will be similar to those of non-retarded persons in his own chronological age group.

A Common Misconception

Mental retardation is frequently confused with "mental illness",[1]

[1]T. S. Szasz, M.D., in his book, **The Myth of Mental Illness,** argues that the term "mental illness" is a misnomer. Psychiatric problems, he feels, represent deviations from social, ethical, and political norms and, thus, are not amenable to traditional medical approaches or treatments which are based on physiological or anatomical deviations from a norm.

even though the two problems have traditionally been differentiated in the following respects:

Mental Retardation	"Mental Illness"
1. Deficit in intellectual development and social adaptation.	1. Disorder of thinking, emotion and behavior.
2. Retarded development originating at birth or during early childhood.	2. Occurs at any life period after a phase of normal development.
3. Generally approached and treated as an educational problem.	3. Generally approached and treated as a psychiatric problem.
4. Irreversible condition which may be improved but not "cured" in light of present knowledge.	4. Usually reversible condition which may be 'cured' through proper treatment; spontaneous remission also possible.

Although mental retardation and "mental illness" should not be confused, it must be remembered that mentally retarded persons are also subject to psychological stress and therefore can, and do, develop emotional and behavioral problems.

SERVICES FOR THE MENTALLY RETARDED

The public has been slow to recognize the need for appropriate services for the mentally retarded on a community level. Throughout the nation, serious deficiencies exist in the number and quality of community-based programs. Thus, most communities are not fulfilling their responsibilities to the retarded in such basic areas as day care, special education, vocational training and competitive and sheltered work opportunities. And, while the concept of "full spectrum" community services has remained largely unrealized, the general lack of sound community-based residential programs (e.g., group homes, hostels and apartments) is particularly evident. The need for increased services at the community level is underscored by the fact that traditional institutional programs serve only about four percent (4%), or some 260,000 of America's over six million mentally retarded citizens.

Emphasis on Institutionalization

The establishment of adequate community services has been severely hampered by a long-standing emphasis on institutionalization for persons who cannot easily acquire independent living skills. A common rationale for stressing institutional placement is the belief that the presence of a mentally retarded child or adult represents a serious threat to family harmony and community well being. It was common in the not-too-distant past for professionals

to advise parents to remove a mentally retarded child from the home and sever all emotional ties. In the face of such attitudes, which encourage separation and isolation of the mentally retarded, it is extremely difficult to establish alternatives to institutionalization within the community setting.

Assumed Roles of Institutions

The institution has traditionally served to isolate and protect the retarded from the community — or to protect the community from the retarded. To achieve this end, most institutions have been built far from populated areas. And, since institutions have themselves been isolated, it has proven expedient for them to provide all needed services to their residents, making the institution a multi-purpose, self-contained and independent pseudocommunity. Many new institutions, although built **near** population centers, continue to follow tradition by providing the full array of basic services (e.g., medical departments, hospitals, schools, parks and playgrounds, on-campus stores, etc.) even though the same facilities and services may be available in the community. The expense of this unnecessary duplication of services is staggering. It is now more costly to serve the four percent (4%) of the retarded who are institutionalized than the remaining ninety-six percent (96%), badly in need of services at the community level.

Meeting the Needs of Residents in Institutions

Many of the inadequacies in traditional institutional programs have resulted from the dehumanizing manner in which services are conceived and delivered.

Best-fit Approach. Traditional approaches to programming within residential facilities have followed the rule: "Make the person fit the program". Until recently, few efforts were made to provide for the needs of individual residents. Instead, programs have been designed to meet the needs of large groups, or the majority of the group members. Under such an approach, residents functioning at the lower limits of a group have made little progress, while inappropriately low ceilings of development have been forced upon the group's more capable members.

Group Living. The large group living concept is a product of past attempts to provide strictly custodial care, i.e., maintaining minimal levels of cleanliness and safety, preventing injury to self or others, and providing for the basic life needs of the residents. Large group living has generally resulted in a life of inactivity, or in activities without apparent purpose. There have not been sufficient personnel assigned to groups to provide adequate levels of stimulation and encourage growth and development on an individual basis.

The Assembly Line. Perhaps the most unfortunate result of group living is the "assembly line" method of providing services. Speed

and efficiency are key words when staff-to-resident ratios are based on custodial approaches. When the bulk of the direct care personnel's time is devoted to feeding, dressing and bathing, time and efficiency become critical factors. Residents become products on a factory assembly line — each "part" handled or inspected by a different and highly specialized person. It is not uncommin to find total groups — especially groups of young or physically handicapped residents — subjected to highly mechanized and impersonal bathing procedures in which staff members are assigned specific tasks: One removes clothing, another soaps and rinses, another dries and dresses, or still another controls traffic to and from the central living area. Similar approaches are frequently used during mealtimes, toileting, and dressing. In such an environment, there is little, if any encouragement for a resident to develop individual skills and abilities. In some cases, the assembly line approach is geared to the needs of the least capable members of the group. Other members are simply not allowed to develop — or worse, denied the right to use skills they have previously learned.

Service Delivery Systems. Traditionally, institutional programs are filtered through a departmental organization structure. A typical structure finds a multitude of departments responsible for planning and implementing education and training programs for the resident population. In large institutions, it is not uncommon to find that the departments responsible for training are uncoordinated, uncommunicative and involved in struggles for power and autonomy. More time and energy may be spent in resolving departmental differences than in planning for the education and training of the residents.

The Role of Parents

Traditionally, parents or guardians of institutionalized mentally retarded persons have not been adequately involved in decision-making and program planning. This unfortunate situation has only served to further isolate the retarded resident from members of his family.

The inadequate lines of communication which frequently exist between families and institutional personnel are due, in part, to the negative stereotypes of parents of retarded children which have achieved the status of prominent folk myths in the professional lore. Parents of the retarded are sometimes viewed by the professional as having little to offer in the way of relevant information regarding their child's needs, feelings, problems and strengths. A rich source of data for the formulation of program plans is, therefore, often totally ignored or, at best, glossed over with minimal interest.

There has also been a tendency for institutional staff to withhold certain information from the parent (e.g., the score which the child has achieved on an I.Q. test, the type and dosage of medication

which he is taking, or the rationale for modifying his training program or changing his living unit assignment). This "veil of secrecy" is usually justified on the grounds that the parent is somehow unable to "handle" such information. This strategy is frequently coupled with the myth of professional omnipotence, which holds that only those persons in possession of certain esoteric degrees are capable of making sage decisions regarding another individual's future.

Additionally, professionals often assume that parents of the retarded are guilt-ridden, ambivalent and rejecting toward their children, and fraught with emotional problems and conflicts. The parents, then, are often viewed by the institutional staff as good candidates for "psychotherapy". These ill-conceived caricatures have been reinforced by a number of articles in the professional literature.

While these and a number of other negative models of the parent are prevalent in the field, it would be far more accurate to view the typical parent of a retarded child as an intelligent and concerned individual capable of, and entitled to, full involvement in planning and decision-making regarding his child's current and future needs.

The blame for poor communications between parents and staff cannot be placed solely on the shoulders of institutional personnel. Many parents lack indepth knowledge of what constitutes sound residential programming. They are sometimes hesitant to ask questions and express their concerns regarding services provided by the institution — for fear of exhibiting a lack of knowledge. Such an approach quite probably reinforces any existing attitudes of omnipotence which may be present among staff. Often, parents are wary of complaining about conditions within the institution, believing that any attempt to "rock the boat" might result in some type of retaliation against their child. Regardless of whether this fear has any basis in fact, some parents adopt ingratiating postures and uncritically accept any and all proposals presented by administrators and/or central office staff.

Parents or guardians of institutionalized mentally retarded persons can be, and have been, of great assistance to the institution and its staff. In many facilities, families are encouraged to participate in parent groups and policy-making committees. The result of such efforts is a fruitful partnership between the institution and the consumer representative.

DENIED OR ABRIDGED RIGHTS

There is an ongoing need to insure that the basic rights of mentally retarded persons are safeguarded. Thus, Article I of the International League of Societies for the Mentally Handicapped's **Declaration of General and Special Rights of the Mentally Retarded** states:

> **"A mentally retarded person has the same basic rights as other citizens of the same country and same age."[2]**

Article V of the Declaration further notes that:

> **"Some mentally retarded persons may be unable due to the severity of their handicap, to exercise for themselves all of their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and the right of appeal to higher authorities."**

In reality, however, the rights of the retarded in the community and in the institution have traditionally been abused, abridged, and denied, regardless of the retarded person's ability to exercise these rights.

Practices in the Community

Education. In principle, at least, our nation subscribes to the notion of providing publicly-supported educational opportunities for all of its citizens. We find, however, that large segments of our mentally retarded population continue to be denied access to public school classes. This denial to the right of education is often based on the belief that retarded persons cannot contribute tangibly to society. Other retarded children are excluded from public schools on the grounds that they do not possess sufficient behavior control and/or self-care and verbal skills to make them amenable to traditional school curricula, physical facilities and competencies of existing teaching personnel. It is frequently advocated that it is undesirable to mix the retarded with the non-retarded in an educational setting, and that separate school facilities are thus required. Therefore, it is not uncommon to find the mentally retarded totally segregated from non-retarded students in a school setting. In discussing this issue, the NARC **Policy Statements on the Education of Mentally Retarded Children** (NARC, 1971) state that ". . . a portion of mildly retarded children can function in the mainstream of

[2]The full text of the declaration is presented in Appendix I.

public education, some with and some without supportive services. Some mildly retarded and moderately retarded children should receive their basic instruction in special classes, but can be integrated into the regular education program on an individual basis in specific areas for portions of the school day. Some severe and all profoundly retarded children should receive their basic instruction in self-contained educational units".

The problem, of course, lies more in our concept of education than in the differences between the retarded and non-retarded students.

Marriage. The right of persons who have been identified as mentally retarded to marry and have children has traditionally been denied in the community. It has been thought that if mentally retarded couples have children they: (1) will not be capable of supporting them; (2) will not be adequate parents; and (3) will be prolific in their child bearing practices. Blanket denial of the right to enjoy the intimate companionship afforded by marriage is unwarranted in the case of most mildly retarded persons. If provided with appropriate counseling and support services, the majority of these individuals are capable of supporting a family and exercising parental and social responsibilities.

Personal autonomy. The right of the retarded person to direct his own life is frequently restricted. Persons who are identified as being mentally retarded often find their lives structured and scrutinized by professionals in the community. In effect, if there is continued insistence upon adopting an overly protective, paternalistic posture, the retarded may have no more opportunity to develop independence and autonomy in the community than in the institution.

Housing requirements. The right of the mentally retarded to live independently or semi-independently in the community is greatly restricted by unwarranted and unnecessary "safety codes". Many group homes and apartments which house retarded persons capable of independent living are required by law to have emergency exits, emergency lighting, and fire safety systems which are not required for non-retarded persons living in similar settings. Since few residential structures meet imposed legal requirements, many mentally retarded persons are denied the right to independent living.

Legal rights. Basic legal rights have traditionally differed for retarded and non-retarded persons. Relatively minor legal infractions frequently result in commitments to a residential institution which, in reality, amount to "life sentences". This is in sharp contrast to the non-retarded offender who, after being convicted of a similar offense, may be incarcerated for a specific period of time or be given a probated sentence.

Practices in Residential Facilities

Integration of Men and Women. Retarded persons in institutions have traditionally been denied the right to live in a heterosexual world. They have been deprived of such normal social experiences as having close friends of the opposite sex or participating in "normalized", sexually integrated leisure time activities. This practice fosters a social situation which differs drastically from community living or the family setting. The rather puritanical approach which characterizes many institutions has been extended to the area of staff assignments. Thus, in some cases, it is required that direct care personnel be of the same sex as the residents with whom they are working. In discussing the integration of men and women, the participants at the Stockholm Symposium on Legislative Aspects of Mental Retardation (ILSMH, 1967) concluded:

> **"Being fully mindful of the need to preserve the necessary safeguards in relations between mentally retarded men and women, the members of the Symposium are of the opinion that the dangers involved have been greatly exaggerated in the past. This has often resulted in unfortunate segregation of the sexes in an unnatural way and has militated against their interests and proper development."**

It was further noted that experience in some countries has shown it is advantageous to mix men and women in residential facilities in a manner approximating normal living conditions.

Education and training programs. Mentally retarded residents have traditionally been denied the right to training and education programs which would maximize their human qualities and dignity and foster the development of self-help and independent living skills. Instead, they are placed in an environment which is characterized by dependency and dehumanizing over-protection. Thus, feeding, dressing, bathing, going to bed and getting up in the morning are often scheduled for the convenience of the staff rather than the needs of the mentally retarded. Residents are frequently required to have close-cropped hair as a substitute for teaching adequate grooming skills. Rather than teaching residents to handle money, they are often required to carry coupons or tokens.

Exploitation. The right to be compensated for work has typically been denied or abridged in the institutional setting. Many institutions depend largely on resident labor in such areas as buildings and grounds maintenance, food service and laundry. It is not uncommon for residents working on a regularly assigned job to be paid no more than $1.00 or $2.00 per month. Such practices are rationalized as "vocational therapy" or "training", even though the "trainees" may spend many years at the same job, with no opportunity for advancement or placement in a community work

setting. Compensation for work should, of course, be dependent upon the quantity and quality of job performance. Different standards of compensation should not be applied to the staff and resident when work abilities are similar.

Discipline. In many institutions, harsh and unusual methods of training and discipline are employed (e.g., physical restraint, non-systematic isolation and chemical restraint) in an attempt to control or punish the mentally retarded. Methods of training and control should be no different for retarded and non-retarded persons. The public school, for example, would find itself in an embarrassing situation if it were disclosed that pupils were tied to the chairs to ensure that they remained at their desks, were locked in dark isolation rooms without supervision for minor infractions, or were prescribed tranquilizing medications to reduce activity levels for the convenience of the teaching staff. Traditionally, distinctly different codes for child abuse are applied in the community and in the institution. In many cases, parents are prosecuted for tying, restraining, or isolating their children, while the same practices are condoned in some institutions under the heading of "treatment procedures".

References

ACFMR. **Standards for Residential Facilities for the Mentally Retarded.** Chicago: Accreditation Council for Facilities for the Mentally Retarded, 1971.

Benda, C. E. Psychopathology of childhood. In: L. Carmichael (Ed.) **Manual of Child Psychiatry.** (2nd Ed.) New York: Wiley, 1954, 1115.

Doll, E. A. The essentials of an inclusive concept of mental retardation. **American Journal of Mental Deficiency,** 1941, 46, 217.

Heber, R. **A Manual on Terminology and Classification.** In Mental Retardation Monograph Supplement to: **American Journal of Mental Deficiency,** September 1959, 64, 2.

Heber, R. Modifications in the manual on terminology and classification in mental retardation. **American Journal of Mental Deficiency,** 1961, 65, 499-500.

Masland, R. Mental retardation. In: Fishbein, M., **Birth Defects,** Philadelphia: J. P. Lipton Company, 1963.

NARC. **Fact Sheet.** Arlington, Texas: National Association for Retarded Children, 1971.

NARC. **Policy Statements on Residential Care.** Arlington, Texas: National Association for Retarded Children, 1968.

ILSMH. **Legislative Aspects of Mental Retardation.** Stockholm: International League of Societies for the Mentally Handicapped, 1967.

APPENDIX I

Declaration of general and special rights of the mentally retarded

International League of Societies for the Mentally Handicapped

WHEREAS the universal declaration of human rights, adopted by the United Nations, proclaims that all of the human family, without distinction of any kind, have equal and inalienable rights of human dignity and freedom;

WHEREAS the declaration of the right of the child, adopted by the United Nations, proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition.

Now Therefore

The International League of Societies for the Mentally Handicapped expresses the general and special rights of the mentally retarded as follows:

ARTICLE I

The mentally retarded person has the same basic right as other citizens of the same country and same age.

ARTICLE II

The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reason of the costs involved.

ARTICLE III

The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

ARTICLE IV

The mentally retarded person has a right to live with his own family or with fosterparents; to participate in all aspects of community life; and to be provided with appropriate leisure time activities. If care in an institution becomes necessary it should be in surroundings and under circumstances as close to normal living as possible.

ARTICLE V

The mentally retarded person has a right to a qualified guardian when this is required to protect his personal wellbeing and interest. No person rendering direct services to the mentally retarded should also serve as his guardian.

ARTICLE VI

The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If accused, he has a right to a fair trial with full recognition being given to his degree of responsibility.

ARTICLE VII

Some mentally retarded persons may be unable due to the severity of their handicap, to exercise for themselves all of their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.

ABOVE ALL — THE MENTALLY RETARDED PERSON HAS THE RIGHT TO RESPECT.

October 24, 1968.